

**Policy Study On**

# ALZHEIMER'S DISEASE CARE



**Office of the Maryland Attorney General**

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Director, Health Policy Development  
*January 2004***

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## PREFACE and ACKNOWLEDGMENTS

Alzheimer's disease (AD) is a devastating illness, for the patient and the family. The individual, the loved one who has always been there, is slowly lost, piece by piece. Caring for an AD patient can be a heavy emotional, financial, and physical burden. Those who provide this care, both family members and skilled professionals, deserve the deepest admiration. So do those who have devoted their scientific skills to unraveling the cause of AD and pursuing preventive measures and effective treatments.

A comprehensive examination of AD-related State policy would need to address bedrock issues about the delivery and financing of care for the 85,000 Marylanders who now have the disease and for the hundreds of thousands of people who will become AD patients as the baby boom cohort ages. So ambitious an undertaking is beyond the resources of this office. Although this report is not comprehensive, it does discuss a number of the legal and policy issues that help determine the environment in which AD care is delivered. State law can have a dramatic effect, for example, on whether a patient with AD can get needed services in the community instead of in a nursing home, a person with mild AD can continue to drive, or someone whose genes put the person at a higher risk of future AD can buy long-term care insurance. The right outcome on these and other public policy matters can make a real difference in the lives of AD patients and their families.

I want to recognize Assistant Attorney General Jack Schwartz for his leadership of this project. He reviewed the pertinent literature, interviewed experts, met with those directly affected by this ailment, and wrote the report. I also want to thank Assistant Attorney General Elizabeth Kameen, who contributed significantly to several chapters, and Andrea Cooper and Kathleen Izdebski for their excellent design work on the report. Many others in the Attorney General's Office also contributed valuable comments and suggestions.

The process of preparing this report was an open and collaborative one. We shared drafts of the report with the public and got many helpful comments, too many to acknowledge individually. I do want to express particular gratitude, however, for the support of the Greater Maryland Chapter of the Alzheimer's Association, led by Cass Naugle; the members of the Elder Law Section of the Maryland State Bar Association; and Dr. William Reichel and former Delegate Peter

Callas, who were particularly gracious in helping get the project off on the right footing. Finally, I want to acknowledge the importance of the Joint Conference on Legal/Ethical Issues in the Progression of Dementia, held in Athens, Georgia in late 2000. This conference was jointly sponsored by five leading organizations: the Borchard Foundation Center on Law and Aging, the Alzheimer's Association, the American Bar Association's Commission on Legal Problems of the Elderly (since renamed the Commission on Law and Aging), the National Academy of Elder Law Attorneys, and the University of Georgia School of Law. The seminal work of this conference was the main stimulus and foremost resource for our project in Maryland.

I recognize that lawyers and public officials cannot do much to directly ease the burden of AD. What we can do, however, is learn how our laws and policies affect AD patients, their families, and their professional caregivers. We want Maryland to be a place where law and policy support high-quality care for those with AD, promote ethical research into AD, and prohibit genetic discrimination against those at heightened risk of AD. The road to achieving this goal is long, but it is important to take the first steps.

J. Joseph Curran, Jr.  
*Attorney General*  
*January 2004*

## **Summary of Recommendations**

This report contains two dozen recommendations across a variety of policy domains related to Alzheimer’s disease (AD). They appear in full within each chapter (there are no recommendations in Chapter 1) and are summarized as follows:

### **Proxy Decision Making in the Clinical Setting (Chapter 2)**

- The Department of Aging and the Office of the Attorney General, in conjunction with the Advisory Council on Quality Care at the End of Life, the Alzheimer’s Association, and other interested groups, should develop a Maryland guide for serving as a health care proxy for a patient with AD. (Recommendation 2-1.)

### **Proxy Decision Making in the Research Setting (Chapter 2)**

- The General Assembly should amend the Health Care Decisions Act to clarify the circumstances under which research participation is encompassed by the Act’s definition of “health care.” (Recommendation 2-2.)

### **End-of-Life Decisionmaking by Public Guardians (Chapter 3)**

- The Departments of Aging and Human Resources and local agencies and departments should support the study of public guardians by researchers at the Johns Hopkins University and, when the research findings are made available, consider whether additional continuing education or other efforts are appropriate to improve end-of-life decisionmaking on behalf of wards with AD. (Recommendation 3-1.)

## **Health Care Planning Through Advance Directives (Chapter 4)**

- The State Advisory Council on Quality Care at the End of Life should review the current Maryland advance directive forms and consider whether a single, optional form that encourages the designation of a health care agent should replace the two forms now set out in the Health Care Decisions Act and whether the materials accompanying the form should encourage the informal expression of preferences and values, rather than instructions about specific life-sustaining medical treatments. (Recommendation 4-1.)
- The State Advisory Council on Quality Care at the End of Life should review Maryland health care facilities' implementation of the federal Patient Self-Determination Act and its Maryland counterpart, § 5-615 of the Health-General Article, to identify best practices and to develop more effective strategies for public and patient education and engagement. (Recommendation 4-2.)
- The State Advisory Council on Quality Care at the End of Life should consider how advance directives and other tools of advance care planning can most effectively be made available to cultural and linguistic minority groups. As a first step, consideration should be given to translating advance directive forms and related materials into Spanish. (Recommendation 4-3.)

## **Planning for Future Research Participation (Chapter 4)**

- The Health Policy Division of the Attorney General's Office should explore the feasibility of an empirical study of research advance directives, with the goal of basing future policy recommendations on the data analysis. (Recommendation 4-4.)

## **Planning for Everyday Financial Matters After Incapacity (Chapter 5)**

- The General Assembly should enact legislation requiring preprinted durable power of attorney forms (other than those used by lawyers or financial institutions under circumstances that allow for personal explanation of the document's significance) to contain a plainly worded disclosure about the effect of executing the document. (Recommendation 5-1.)

## **Medicaid: Access to Appropriate Care (Chapter 6)**

- The Medicaid Program should take steps to assure that its participating managed care and peer review organizations do not deem a service to be medically unnecessary or inappropriate for a patient based solely on the fact that the patient has been diagnosed with AD. (Recommendation 6-1.)

## **Medicaid: Level of Care Determinations (Chapter 6)**

- The Medicaid Program should take appropriate steps to revise the level of care assessment tool as promptly as possible and work in collaboration with the Alzheimer's Association to enhance the sensitivity of the tool for AD patients. (Recommendation 6-2.)
- The Medicaid Program should promptly review whether Transmittal 135 has outlived its usefulness and should be replaced. (Recommendation 6-3.)

## **Medicaid: Hospice Care (Chapter 6)**

- The Medicaid Program should consult with representatives of nursing homes and hospice to consider how to remove financial disincentives to the use of hospice in nursing homes. (Recommendation 6-4.)

## **Nursing Home Regulation (Chapter 7)**

- Surveyors from the Office of Health Care Quality should be provided with suitable training regarding the use of feeding tubes for patients with AD, including the clinical indications and legal criteria justifying the withholding or withdrawal of a feeding tube. (Recommendation 7-1.)
- The Office of Health Care Quality should continue to emphasize to its licensees that its surveys will give priority attention to evidence of appropriate pain assessment and management and train its surveyors to be particularly vigilant about this aspect of quality care. (Recommendation 7-2.)
- The associations representing nursing homes should give priority to educational efforts to convey best practices in pain assessment and management, with particular emphasis on tools that permit pain in people with AD to be measured and documented (by, for example, consistent observation of well-defined aspects of breathing, vocalization, facial expression, and body language). (Recommendation 7-3.)

## **Assisted Living Regulation (Chapter 7)**

- As resources permit, the Office of Health Care Quality should conduct or sponsor a study to determine whether advertising claims about special AD care are consistent with descriptions in disclosure statements and whether both are consistent with services actually delivered. (Recommendation 7-4.)

## **Patient Abuse and Exploitation (Chapter 8)**

- The Department of Aging should convene a meeting of interested parties to begin the process of identifying, pilot testing, and promoting a well-designed and validated abuse prevention program in Maryland nursing homes and assisted living facilities. (Recommendation 8-1.)
- The Department of Human Resources should work with interested groups to consider the need for improved services to victims of dementia-related domestic violence and the individuals with AD who have acted violently as a consequence of their disease and increase awareness of the risk posed by an AD patient's having access to firearms in the home and the safety measures that might be taken. (Recommendation 8-2.)

## **Genetic Discrimination (Chapter 9)**

- The General Assembly should prohibit genetic discrimination in long-term care insurance. (Recommendation 9-1.)

## **Driving and other Transportation Issues (Chapter 10)**

- The Motor Vehicle Administration should continue developing its model drivers' assessment program, especially its effort to encourage physicians to make the link between specific assessment tools and reporting to MVA. (Recommendation 10-1.)
- Med Chi, the State medical society, should encourage its members to participate in the MVA's program. (Recommendation 10-2.)
- The General Assembly should base any new legislation concerning the licensing of older drivers on the data and research findings that will derive from the Driver Safety Research Program. (Recommendation 10-3.)

- The Maryland Insurance Administration should gather information about health insurance coverage of physical or occupational therapy or similar health care services needed for purposes of continued driving and, if its inquiry suggests that coverage is commonly denied, consider an appropriate response to the problem. (Recommendation 10-4.)
- The Maryland Transit Administration should continue its ongoing effort to adapt the current public transportation system to the transportation needs of those whose health precludes their driving and that it work closely with the Alzheimer's Association and other groups to assess in particular the demands for alternative transportation that the increased incidence of AD over the next two decades will generate. (Recommendation 10-5.)